

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR PLANNING THE ANNUAL  
STRATEGIC PLAN UPDATING PROCESS  
CONFERENCE CALL

WEDNESDAY, AUGUST 5, 2009

The conference call meeting came to order at 2:00 p.m., Thomas Insel, Chair, presiding.

PRESENT:

THOMAS R. INSEL, M.D., IACC Chair, National Institute of Mental Health

DELLA HANN, Ph.D., IACC Executive Secretary, Office of Autism Research Coordination, National Institute of Mental Health, and Designated Federal Official

ELLEN W. BLACKWELL, M.S.W., Center for Medicare and Medicaid Services

LEE GROSSMAN, Autism Society

LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds

CATHY RICE, Ph.D., Centers for Disease Control and Prevention

ALISON TEPPER SINGER, M.B.A., Autism Science Foundation

EDWIN TREVATHAN, M.D., M.P.H., Centers for Disease Control and Prevention

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## PROCEEDINGS

2:00 p.m.

Dr. Insel: Welcome everyone to IACC Planning Subcommittee meeting to talk a little bit about the September workshop. Can I ask who is on the call at this point?

Participants introduced: Ed Trevathan, Cathy Rice, Lee Grossman, Alison Singer, Lyn Redwood, Ellen Blackwell.

Dr. Insel: Anyone else? Okay. Thank you everyone for taking some time out in the middle of summer to do this. The business in front of us is to come up with a process to select the people for the September workshop.

I want to remind you that when we talked about this the last time that we weren't looking to rewrite the plan but to bring together a group that would help us to look at the plan we have, look at the portfolio analysis that's been done and then to ask where do we go from here--the changes that can

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be made based on new research findings, new insights, or based on the topics that were reputed on in December and January and use this as our opportunity to come back to them.

So what we are about today is to identify who we have do that. When we discussed this before we talked about having clinicians, a researcher that had family or personal relationship with someone with autism in each of the panels. Remember we had six goals but we reduced that to five panels that we took five and six and combined them and when we last talked about this at the full IACC meeting if I have this right that we discussed having two people in each of the categories-- clinician, family and personal researcher for each of the five panels. So that would mean that there would be basically six per group plus the IACC liaison which would be drawn from the subcommittee or the larger IACC subcommittee. What we did at the last meeting

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is we asked for nominations, to have them sent in and what we got as you should have received the list broken up by each of the five panels in each of these categories. What we need to do today is find the best way to pair these down so as to looking at a list of 30 or 40 names for each of these categories that we are down to 5 or 6. So let me make sure that is clear before go on. Questions?

Ms. Redwood: Tom, I have a question. In reviewing the recommendation that we have before us there's several times where there's an overlap with regard to nominations in different categories and with regard to categories with IACC liaison. So I would like to know how you would like for us to handle that on the call today?

Dr. Insel: There are a couple of options there. If we just take the IACC liaison piece it will really be best to identify with one of these panels and not more

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than one. Maybe what we can do is simply figure out how we can divide them up. If we don't have enough people from the names maybe we can go back to the committee and ask for someone else to join in. I do think it would be good to have two liaisons for each of the panels and hopefully that would include, if it's possible, a Federal member and a public partner if we can do it. But, as you say, this is often the way it happens here. You get the same names on the same list.

Ms. Blackwell: I seem to recall when we talked about bringing in other members of the IACC who are not participating on the Strategic Planning Subcommittee. Would we want to think about having an additional IACC representative who is not on the Strategic Planning Subcommittee who is a liaison?

Dr. Insel: We do already. The nominations came from the whole panel. Any other questions about how best to do this? So

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let me tell you what we were thinking about. We talked about this yesterday trying to figure out the best process because we've got a lot of names here and, of course, this is like everything else you do at public meetings so we're not going to be inviting anybody here to say particularly negative things or to vote on any of the names that are here. But what we want to do with you today is let you know that there is new information so that the person that's being nominated is what the reason would be. What we were hoping was that we could use this meeting today for you to go through the list so that we could all be educated about the roster of names and specifically anybody who you feel could bring something critical to this process that might have been left out previously. You should have received, just as a reminder, who served on the 2008 workshop so you can see who was there before. We would like to have some

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fresh ideas brought into the process so that so as you look at these names we want to make sure we get all of those ideas as part of this discussion. What we thought we would do is if we could get through this list and hear about specific nominees who you think the committee really needs to know about. We've come back to you for an electronic vote and we can do this very quickly with an electronic ballot that we would send to you. What we would like do, because we don't know how much overlap there will be, is we would like for you to nominate 3 people, not just 2, in each of the categories. And I think if we could rank order them, listed as 1, 2, or 3, if that helps, that would be useful as well and then we could put the names together and come up with a final tally of the top 2 in each category. We're talking about a total of 30 people and one possibility is that if we have let's say, an additional 15 names from those

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nominations. If somebody can't make it on September 30<sup>th</sup> then we would have a backup that we can go to and then we won't have to go back to this process again. Tell me how you feel about that process as we're going forward.

Mr. Grossman: I want to congratulate you for your thoughtfulness on that. That seems as a way to make this process simpler and certainly maintain as democratic objectivity so I think that is a great idea.

Dr. Insel: Any other questions or comments?

Dr. Trevathan: I just have a procedural question. If there's someone who has been nominated or who doesn't show up on the list, how do we determine that or how does that work? Like there may be a question under Panel number 3 -- I thought there were other liaisons that might have been.

Dr. Insel: I'm going to turn that

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question to Della. She is more up-to-date on the process here.

Dr. Hann: I think through your discussion today as we move through each Panel--I assume we're going to go somewhat systematically. If there are other names for any of those categories that come up in discussion today that you all are interested in I think this is the venue to have that kind of discussion. It can certainly be added essentially at this point because this is your opportunity to do so. That would include the other IACC members. You know, though, that the other IACC members were give the opportunity to self-nominate so if their names are not here they may or may not be interested and fulfilling that role would mean some additional time and attention from whomever is filling it.

Dr. Insel: Let's talk about that quickly. That is an important point. This

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IACC liaison job is more than just being the meeting. What we were hoping is that the two people for each of the panels would put their heads together and bring things to the table through conference calls. We can help you set all of these up to get a very rich discussion going about what we know as far as the plan in terms of the portfolio analysis and to start to flush out what the changes might be so that when you come to the meeting on the 30<sup>th</sup> most of the work would be done. The 30<sup>th</sup> is really an opportunity to point out to a larger group I don't think that the meeting on the 30<sup>th</sup> would be the time to begin to put new ideas on the table. There may be things that would come out from discussion that were missed during previous discussions but we really see this as most of the work going on ahead of time so that will come with a really clear sense of what they want to convey to the larger group. There's not going to be a lot

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of time so it will be a 30 minute or so presentation or so and we'll go through with you what we've been thinking about for the agenda. But given the amount of time, what to cover, you will have to do it ahead of time. And, as I said, we're prepared to help on the setting up of conference calls, getting people together once we get the names. Anything else before we plunge into this? I guess the best way to do it is go through one by one here and start with Panel 1. Does everybody have a list in front of them that it should say DRAFT IACC nominations for 2009 Scientific Workshop Panel and then there are 5 pages in each one has a list for clinicians, family personal researchers, IACC liaisons. Everybody's got that? Tell me what the addendum is.

Dr. Hann: About an hour and a half or so ago we sent out an addendum of late breaking suggestions. So there are really two things on this--the addendum as well as the

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bulk of the document that has the names.

Dr. Insel: One way to do this is simply to ask within the clinician category if there are specific names that you want the rest of the group to know about. This is sort of a campaign that you are given the chance to tell your colleagues that someone has special attributes which you think that make them more suitable putting into this role. So I'm just going to open it up and ask for your best recommendations and maybe very briefly give us some insight because I suspect that most of us do not know these people. Maybe I'll start by just picking the names from the list: Rebecca Landa and Geri Dawson. Both are clinicians and have enormous clinical experience on early phases of autism. Rebecca, in particular, is known for trying to come up with ways to detecting autism before 12 months in children at risk. They have some; I would call it, special knowledge as clinicians from early on.

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Dr. Trevathan: I would just echo that. Robin Hansen also has that background. I know she has experience in looking at developmental screening instruments in other countries and is really quite experienced and sophisticated in the clinician in this area.

Mr. Grossman: Rebecca is certainly one of the people that I had circled and would be great in the clinician area or the research area for Panel 1, but I also want to put a plug in for Derrick McFabe, who presented at our conference two weeks ago. He's from Western Ontario and has just amazing resources on numerous factors of prenatal potential for why autism may develop and certainly postnatal. He spoke for hours about research currently in Ontario and worldwide. And I would like to also put a plug also in the addendum for Kathy Martien at MGH in any of the clinician categories for any of the

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panels. I would highly recommend her because she has an extensive experience with people with autism and is very varied and had some of the best presentations I've heard to date.

Dr. Insel: That's very helpful. Any other comments?

Dr. Shore: Another item to the addendum would be Jim Ball because he has extensive experience as a clinician on the educational end of things. That could also be useful in case something was missed during the early intervention stages.

Dr. Insel: Any other comments under the names of clinicians? Okay, let's go on to the Family/Personal column. Again, someone pointed out that many of these names will show up over and over again but we want to make sure that we at least know about anybody you feel would be particularly helpful with this Panel 1.

Mr. Grossman: I guess I'll keep speaking

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up. People that were high on my list were Paula Durbin-Westby of West Beach. I know that she would be a very good team player on a panel I think would have a lot to offer. Jane Johnson has tremendous experience and is respected by many in the autism community. And then I added Marguerite Colston to the addendum. Marguerite has been very active in the Maryland area and is active in numerous programs involving having a child with multiple medical issues.

Ms. Redwood: Tom, I would like to put a plug in for Peter Bell. Peter has been involved in the autism community for years initially with Autism Now. I think he's very well versed and is able to represent a broad community with his past experience.

Ms. Blackwell: I would concur with both Lee and Lyn. I know both Peter and Marguerite and I know that would both do great on this panel.

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Ms. Singer: I am going to agree with the nomination of Paula. I also want to put a plug in for Nancy Wiseman who is a parent and has devoted many years of her life since her daughter has been diagnosed. I think she would be a great asset as well.

Dr. Insel: Okay, how about on the research end? We talked about Rebecca Landa and Robert Hansen already as people who have done some of the important research in this area. Cathy Lord, I believe, is the person who has helped us with the initial panel. She chaired this group before and is someone who has been very active in the issues of screening development of screening instruments and tools for detection at an extensive level.

Mr. Grossman: I would agree with Rebecca and Ken for Research and I would put in Debbie Fein's name in there as well.

Dr. Trevathan: I would like to mention John Constantino. He's one of those folks

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that could be under the clinician or the research category. He is a very sophisticated clinician; both board certified pediatrics and child psychiatry. He actually has done a lot of work in screening of children in a variety of populations, siblings of children with autism, the general population and one with very young children and I think he has extremely broad expertise and I've seen him work well in committees so I would say John would be good and I also know that Robin and Rebecca are also excellent.

Dr. Insel: We should maybe mention in addition to other comments, Debbie Fein gave a talk at IMFAR on recovery, which is what I thought was very important with a new approach and a lot of fresh ideas. That was one of the plenary addresses that got big uptake up there so another reason to think about bringing her into some part of this or somewhere in the course of one of these five panels. Anything

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else on the research end? Do you want to deal with the liaison piece now or do you want to come back to it? We have the opportunity, I guess, to volunteer our colleagues who are not on the call! What's your sense of this group? I'm assuming everybody knows everyone? Do you know who Jennifer Johnson is?

Dr. Hann: Jennifer joined in the spring. She is the new administrator for Children and Family.

Dr. Insel: And there is also a new head of the Office of Disabilities, who will be joining at the next meeting. We could certainly volunteer Henry.

Ms. Blackwell: I was already considering volunteering Henry for the last two panels.

Dr. Insel: I think he'll be baptized quickly here—even before the next IACC meeting, perhaps. We should think about him or later. Okay, we've got to move on to Panel 2 - How Can I Understand What is Happening.

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And we have some of the same names coming up.

Is there anybody here that we haven't heard from before that you want your colleagues to know about?

Mr. Grossman: My plug here would be for both Jim Ball and Bryan Jepson. Both have come out with outstanding books on exactly that subject.

Ms. Singer: I would like to put a plug in for Craig Newschaffer for here. I think the early studies are something we need to know about and he's heading up the EARLI studies I understand so I think he would be a great asset.

Ms. Redwood: I want to put a plug in for Dr Jepson and point out that he was also a part of the planning process last year and participated in one of the workshops.

Dr. Insel: Sarah Spence is a clinician who was in the group at UCLA for many years and then about three years ago moved to the

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intramural program at NIH she's a child neurologist who has been a key player for the large scale intramural effort. So she is very experienced about the full range of autism.

Dr. Trevathan: Also Polly, a pediatric neurologist, who set up on the research centers has been on the front end of a lot of clinical activity and has been involved with the Academy of Pediatrics on the child neurology side in developing practice guidelines for the initial treatment evaluation and sorts of testing that have to be done on children and so she has a lot of experience not only as a clinician but also on working on committees like this to develop guidelines and scientific agendas. I think for those reasons she would be quite good.

Dr. Insel: Is she at UC Irvine?

Dr. Trevathan: Yes. You would be hard pressed to find someone in the area of clinical research that Polly hasn't touched

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upon.

Dr. Insel: Any other recommendations from the clinical category? What about the Family/Personal line?

Ms. Singer: I would like to put a plug in for Ashura Buckley, who is the sister of a 30-year-old man with autism. She's also a neuroscientist who is finishing up a three-year fellowship at NIH. Her work focus is on sleep with regard to autism; not necessarily sleep hygiene but, more specifically, she is doing brain scans of individuals with autism during sleep with reference to their sleep pattern issues. I think her work is really very new and very interesting and she has a sister as an adult to contribute.

Dr. Trevathan: I would like to put in a plug for Nick Dubin, who has just recently completed a doctoral degree. He is on the autism spectrum and he has plenty of practice and has written a book and specializes in

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areas such as autism and bullying and autism and depression and I think he would be really good.

Mr. Grossman: My strongest endorsement would be for David Humphrey. David is one of the original founders of ATN and is involved in very cutting-edge programs internationally; he is running a treatment program in Asia right now and has great experience in a broad basis across the spectrum and life span. Also would like to put in an endorsement for Jim Adams from Arizona State. Jim has published quite a bit and done a lot of research about what is happening. And lastly, I would like to put a plug in for Valerie Paradiz. She has a son on the spectrum and much of her research and what she lectures about is in this category as well.

Ms. Redwood: I was going to put in a plug for Mark Blaxill. I've personally worked for Mark for a decade now and I think he is

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very thoughtful and scientific and he comes specifically from a parent perspective and actually what happened to his daughter and let's just say I get a little concerned about having researchers on this role of Family/Personal and I think it would create Mark doing a really good job in that area.

Dr. Trevathan: Stacey Ramirez, whom I don't think I met personally but know of her work. She is a mother of a child with autism here in Atlanta. She actually has been very active locally and works for the university centers of disability here at Georgia State University so she has experience with services in the community and, of course, as a parent.

Ms. Blackwell: Ed, I also know Stacey but for a different panel so I agree that we should definitely get her on one of the panels.

Dr. Insel: One name that is on here is misspelled, so just to clarify - it's Don

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Rosenstein. He may not be known to most of you. Don was the clinical director of NIMH and of the medical board for the clinical center of NIMH, who left about a year ago because his 14-year-old son wasn't getting the support they needed here in Maryland. They got better autism services in North Carolina so he's now part of the cancer center at UNC where he's developing a whole new program for, I think it's called, psychiatric psychology or something like that. But he's an extraordinary clinician and person who has become involved with autism more recently and I know he has served on some other panels we've done and he's been a great team member and somebody who everybody has worked well with so just thought I'd let you know who that is. Any other comments on that roster? What about researchers?

Mr. Grossman: I was wondering if we could choose that whole group.

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Dr. Insel: Yeah, it's a great group of people and maybe what we'll do is have a chance to see some of them fill out some of the other categories here.

Mr. Grossman: It's very impressive but two that I would go with here are Martha Herbert and Craig Newschaffer, so I guess those are my two out of truly an all-star cast there.

Dr. Insel: Let me ask if there are any names that are not familiar. Anybody want to plug for any of the other names? Certainly I guess David Amaral was the chair of the other project, the earlier discussion and Martha Herbert was involved and Craig Newscheffer was involved and I think maybe Joe Piven had been here before as well. And Joe is someone who could serve either on the research end or the clinician end because he's been very active as a clinician as well as a scientist.

Dr. Trevathan: Chris Walsh, who is

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probably known to everybody. I don't believe he was involved before but he is a neurologist and a very experienced clinician but he's also really cutting edge in terms of his genetics research. I guess one thing that is essential in having him involved is because he had a lot of experience and has had a lot of success putting together relatively large collaborative groups which I know is an area of emphasis and I think will work well.

Dr. Insel: I think he is head of the Scientific Board for the Advisory Consortium in Boston. He has had a role there along with Martha Herbert who is part of that group. And I think Dan Geshwind is known to everyone as well. He has been involved in autism especially around genetics and neurobiology. Okay, moving on and looking at Panel 3 - What Caused it to Happen and Can It Be Prevented - and we have a list of clinicians and it starts with Ed Cook and it ends with Lonnie

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Zweigenbaum.

Mr. Grossman: My number one choice here was Bob Hendren, whose most recent position is Head of Child Psychiatry at UC San Francisco. He also is currently the President of the American Academy of Child and Adolescence Psychiatry.

Ms. Singer: I'll put in for Lonnie Zweigenbaum, who heads up the Babies Research Consortium and who I think was not able to participate in the first round but I think really has a lot to add here.

Ms. Redwood: I would like to put in a plug for Daniel Rossignol. He's a parent of a child with autism and also has a very large clinical practice and he's with the International Child Development Research Center.

Dr. Insel: Anything else from this list? On the Family/Personal side?

Dr. Trevathan: I would like to put in a

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plug for Temple Grandin. I think people know Temple is. Another person who I noticed who might be good is Lars Perner for Family/Personal.

Mr. Grossman: He's a Professor of Marketing at the School of Business at the University of Southern California. One of the other people that I added is Jeff Sell who has twin boys with autism and he's done a lot of work saying how this happened, how this can be prevented so somebody I would add to the list.

Ms. Redwood: Also I would like to put a plug in for Sallie Bernard. Sally was originally with Cure Autism Now out in California. She's been a board member and now with Autism Speaks and she's been just extremely knowledgeable and knowing autism research for over a decade now as well as privately funded research.

Dr. Insel: I know Denise Resnick, but in case you don't, she was the Director of SARRC,

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Southwest Autism Research and Resource Center.

It's a very large center and it is based in Phoenix but it does serve the entire Southwest. Denise was very involved with earlier IACC but not with the current committee and she's someone who has been working with the DoD effort and follows closely what's going on in autism both locally and nationally and has been a great advocate for families and for people on the spectrum especially in Arizona. She is very closely connected to Cindy McCain, I guess, who is the chairman of her board, and I am sure would be eager to help in this effort. What about Researchers here?

Dr. Trevathan: Well, the two that jump out at me right away are Martha Herbert and Steven Edelson.

Ms. Redwood: And also I want to point out Isaac Pessah. Isaac also brings to the table research and environmental factors so I

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think he would be a nice addition there too and I believe Isaac was part of the previous workshops and also Irva. Irva has done a lot of research and I also think she would be a nice addition to the panel.

Dr. Insel: If I could say something about Isaac Pessah. He's been part of some of the meetings we've had the last couple of years, since we've looked at initiatives coming up, and my sense of him is that he is always a couple of years ahead of most of his colleagues and I think right now you want somebody who is thinking way out into the future. He's got some very bold ideas about how one would go at the environmental issues.

So I think if we're looking for someone who can provide a plan he may be very helpful.

He's also a very good committee member.

Another in that situation would be Matthew State. Matt is an M.D./Ph.D. from Yale and I guess he's a child psychiatrist but most of

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his time is spent doing cutting edge genomics but more recently looking at the biology that comes from that genomics to try to develop cellular pathways or targets and so he's also somebody else who is very much on the cutting edge.

Mr. Grossman: Just to put my two cents in here - I guess if I were going to choose the dream team of researchers for this it would be Martha and Isaac. I would love to see those two putting their heads together and I agree with what you were saying about Isaac.

I know he has done more work in the field than Martha at this point on the causes and prevention and just probably among the most important panel, I think, and so I put my plug in for those two.

Dr. Insel: Just add one other name that some of you may not know - I'm not sure who recommended her but Rosalind Picard. She's been involved with us. We actually brought

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her in for what we call our NIH series where we want to hear from people on the cutting edge. She's at the Media Center at MIT and has been involved in developing tools for miniaturized devices to monitor physiology outside the laboratory and she's been working with people with autism and to help them monitor their own physical states. She's a very creative, very interesting person, and also a great team player. I don't know if this is the right panel for her. I've jumped ahead? Sorry—my apologies—erase—will bring up later. Anything else on the Researchers for Panel 3?

Dr. Trevathan: Just wanted to throw this out - given the nature of Question 3, I was hoping we would have someone from NIH under IACC liaisons so that NIH related research... I don't know if that's already been considered or not or maybe I don't have the full list. I have Jennifer, Lyn, and me on that list for

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Question 3.

Dr. Insel: Can I assume that these names were self-nominated? Well, if it helps I'm going to nominate Dr. Landis, but you can't tell her I did this! It'll be sort of like the Academy Awards - she'll just be surprised if she gets the award! I think that's a good point, Ed. For that particular category we need a longer list to select from.

Ms. Redwood: What about Sue Swedo? We have Sue Swedo down under the Research category and I think Sue would be a wonderful liaison too within NIH.

Dr. Insel: She's not an IACC member. She's listed as one of the potential researchers there and I guess we can also list her as both. She's somebody who has certainly been active and she recently presented to the IACC so you will know who she is and how she thinks.

Ms. Redwood: Can the IACC members who

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are Federal sit in for them at the meetings?  
I know the public members can't but I was  
under the impression the Federal members could  
so that maybe she could serve that way.

Dr. Insel: Oh, you mean act as a sub?

I would really get the IACC members  
themselves to the table because at the end of  
the day they are going to be the ones that  
have to support the ideas that come forward to  
the rest of the committee and then if Sue were  
to do this and she wasn't at the final meeting  
then it would put that panel at some  
disadvantage so I would rather have permanent  
members in this. I see your point and  
certainly it would be great to have Sue in one  
of these panels someplace because she is  
somebody that thinks broader and she has a lot  
of experience so we should look around and see  
if there's another place to plug her in. It  
may be in this next category since she is the  
one that is pushing anti-inflammatory

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treatments and developing novel interventions.

Maybe we ought to think about adding her into this next category.

Ms. Redwood: I would like to nominate Duane Alexander. I think that Duane would make a good liaison too.

Dr. Insel: We're moving on to Panel 4. We've got a list of clinicians. Lyn - should we add Sue Swedo to this list?

Ms. Redwood: I think that would be fine.

Dr. Insel: So she would be one of your addendum names along with Bob Hendren and Kathy Martien. Which panel do you think Bob might be best at?

Dr. Trevathan: He keynoted our conference last year and did an incredible presentation pulling the two schools of thought of environment and genetics together and really is what I perceive Panel 4 and Panel 3 to be covering. I think Brian Jensen would be an excellent choice for Panel 4 under

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clinician.

Dr. Insel: Does Bob have a lot of clinical experience in treating clinician? When he was at the M.I.N.D. Institute was he more involved on the research side?

Dr. Trevathan: They had a very active clinic there that he oversaw so he was active as anybody that I've seen but I probably would go with Panel 3 for Bob for my choice.

Dr. Insel: I just wonder - it may be great to have him in here someplace but the problem is we would have to split him. What I know about him would be more on the treatment side rather than the genetics environment research side. He's somebody that I would have turned to for thinking about issues that are current.

Ms. Blackwell: I have a question about this list of clinicians. Do any of these folks specialize in working with adults or are they all working mostly with children?

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Ms. Redwood: I think it may seem like more children than adults because that's just because of the demographics we're dealing with right now.

Ms. Blackwell: I did put an adult clinician on Panel 5. I nominated a fellow named Eric Samstad from Johns Hopkins who is working exclusively with adults so maybe we'd like to throw him in on Panel 4. Just a suggestion - he does work mostly with adults with autism.

Dr. Insel: Especially because Panel 4 is pretty thin compared to some of these other groups. That is the one area where, it seems to me, you could cross panel pretty quickly. There's less specificity on the clinical care side. Is there anybody else from 2, 3, or 5 that we want to add in on the Panel 4 clinician list? We've added in Sue Swedo and we have Bob Hendren and Kathy Martien who were added in as part of the addendum as well.

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Dr. Trevathan: In looking at the entire Panel 4, George Jesien, who is the Director of AUCD, Houston University Center on Disability, is really outstanding, knows nationally a lot of what's going on in terms of clinical care. Clinical services and he's involved a lot with running training programs and so forth. I think George would consider himself a researcher and he is very interested in transition to adults committed to the IACC. I don't know that I've ever been to a meeting at IACC where I don't see George in the audience but I think he would actually fit better under the clinician category, but I don't know who nominated George. He would be outstanding. At this stage if we're interested in looking at clinicians that have lots of experience with adolescence and adults, Opal Ousley, who works in the Emery Autism Center, has a lot of experience working with adults and older adolescents.

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Dr. Insel: Ed, your suggestion is we move George Jesien under the clinician line?

Dr. Trevathan: Yes. He has a lot of understanding about what's going on nationally with clinical care, clinical training and clinicians so I think he would be an excellent choice in that group. He's a PhD. The organization that he runs is really large with multiple centers all over the country and there are very large numbers of MDs that he works with.

Dr. Insel: He's at every IACC meeting.

Ms. Redwood: I think it would be important to have an MD and a PhD represented because there are things that MDs do that are a little bit different in terms of medical treatment that you won't get from a PhD perspective.

Ms. Blackwell: Dr. Samstad is a psychiatrist. He has a mental health clinic at Johns Hopkins Bayview. I'm suggesting now

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that perhaps we might want to move him to Question 4. Hopkins runs a Special Needs clinic and it is very difficult to find a clinic that serves adults with autism. And they are local so I was kind of hoping that he might want to participate -- somebody who is in the trenches every day. At the clinic they also do PT, and several types of therapy for treatment--one thing that I really liked about it.

Dr. Insel: Sue Swedo is on the list as a pediatrician so she might have a broad perspective.

Dr. Trevathan: Robin Hansen is a pediatrician - I believe she may be a developmental pediatrician.

Dr. Insel: Anything else on Panel 4 for Clinicians? We're ready to move on to Family/Personal. We've got about 8 names and we've got an additional 5 that were put on the addendum.

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Mr. Grossman: I don't know who added Sharisa to that but that was a good call. I think Sharisa would be a very interesting contributor to this panel. She is not verbal and uses augmented devices to communicate and she's extremely knowledgeable and a brilliant young woman. I added some other names to the list on that addendum. Hannah Cary is a sibling of a young man with autism and she just graduated from George Washington University but is very adept, very knowledgeable about treatment interventions and really was a shining star at our conference two weeks ago. Bill Robinson is a retired judge in Kansas City and devoted much of his time to looking at treatment centers and interventions. And lastly I added Dr. Jim Adams from Arizona State on there as well. I think Jim would be a great addition to this panel.

Ms. Redwood: Katie Wright. Katie Wright

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is very well respected in the autism community. She's left no stone unturned with treatments that she has utilized for her son.

I think Katie would make a wonderful addition to the Family/Personal perspective. As well as Portia Iversen, who is one of the founders of Cure Autism Now.

Dr. Insel: Portia had written this book, Strange Son which talks about her years trying a variety of interventions and the experience that she's had with them.

Ms. Blackwell: Since no one else is going to speak up, I think David Mandell would be a great addition to this category. David has worked with us on a research project over here at CMS and he's very familiar with looking at the advocacy of different treatments and interventions.

Mr. Grossman: I'll put a plug in here for Rosalind Picard that was on the addendum list and I think Tom talked about her earlier

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and I also want to put a heavy endorsement in for David Mank, who is probably somebody that most of you don't know. He's at Indiana University and, as far as I'm concerned, the best person in the country for taking treatment options and making them relevant to the service delivery. He runs the AUCD program at Indiana University and works with the most leading disability organizations in the country in working with taking research of treatments and putting them into practice. He's also started a program with us with adult service delivery.

Ms. Redwood: Jill James, who is listed there, from the University of Arkansas and has been doing research and coming up with specific treatment protocol. I believe she is NIH funded right now and she's also part of the Autism Treatment Network. I think in terms of a researcher and doing treatment research she would be a wonderful addition and

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excellent team player.

Dr. Shore: I think on the addendum I see the name Brenda Myles, so I think would be an excellent person to consider.

Ms. Blackwell: I spoke with Brenda about these dates and although I agree with you, I think she's great, I am not sure she's going to be available.

Dr. Insel: There are other names - Jackie Crawley does animal research, mostly mouse models of autism; Ed Cook you would have met at the last IACC meeting and Sally Rogers and Fred both are involved with large centers of autism research that are currently funded by NIH. We will move on to Panel 5.

Mr. Grossman: I'll speak first on this. The clinician group that's here is excellent; there's no doubt about it but I think that Cathy Pratt is my plug. I don't know of anybody that has done more as far as service delivery than Cathy has over the last number

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of years. I would highly recommend her to be on the clinician end.

Ms. Redwood: And also Doreen Granpeesheh. Doreen is a behavioral analyst and she's been working in this field for 30 years. She is the founder and director of CARD, which is the Center of Autism and Related Disorders and they are known throughout the country and even international.

She's treated thousands of children; she has been on the Dr. Phil show and I think Doreen would help out a lot on the clinician panel here too.

Ms. Blackwell: I've done a lot of thinking about this and I've actually struggled and even talked to Lyn before the call started but I think clinician in the sense about talking about it goes far beyond just treating patients. I also think it matters on how we approach systems of care and, for that reason, I added what might be a

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little unusual - Tec Chapman - Tec actually worked during the Combating Autism Act and Tec is one of the most knowledgeable people about autism and autism services in the United States that I know. In addition to Tec I'm going to throw out Michael Chapman who is the Director of Developmental Disabilities here in the State of Maryland. Because when we talk about services I think we really need to talk about how a system's delivery and not just from a provider's perspective and a much more macro perspective. He's just as fantastic guy. He worked with our Governor here to close Rosewood and he just has an enormous amount of energy.

Dr. Insel: Other names that you want to highlight for the group? Many of these have shown up before so...

Ms. Redwood: I'd like to nominate Henry Claypool, our newest member.

Dr. Insel: You mentioned him before.

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I'm going to see him tomorrow so I'll have a chance to tell him he's been nominated. He clearly would be helpful on this. What about on the Family/Personal side?

Mr. Grossman: Lu Zeph was on the previous IACC and did a great job. I also had on the addendum some other folks - Lisa Endow is a person on the spectrum who was a shining light at our last conference and did an incredible presentation on the culture of autism. I talked about Valerie Paradiz before. Herm Fishbein runs a school in the Miami area. Dr. Fishbein is an expert in adult's area and then the last person I added is Dr. Ruth Sullivan, who I think in terms of services has done more than anybody in the history of autism and if we can get her out of retirement and I'm sure she'll be proud to serve on this committee she would be a great addition as well.

Dr. Insel: Ms. Gernsbacher - She's a

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clinician as well as a family member. She's been very involved and has been an active researcher herself and is specifically interested in this transition independence and again follows the science and a lot about where the service needs to go. Good committee member and someone who has been on many NIH panels. Last year she was the President of the American Psychological Society so she is a very distinguished psychologist but this is not what most of her research is about. The other name on here - Marjorie Solomon is a mother of a child with autism and is also a researcher who trained at Harvard at the M.I.N.D. Institute and very interested outside of her research in advocating for changes in policy particularly for insurance coverage and other kinds of needs for people with autism. She's a name that had been sent forward during the Presidential campaign as a potential IACC member. She's likely to be somebody that we

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meet in the future. She was at the IMFAR meeting where I met her and I think she may have met some of the other members of the committee there.

Ms. Redwood: Also, Laura Bono - she has an adult son with autism. She's been instrumental in legislation.

Dr. Insel: One other thing to mention on this list - Lee mentioned about Lu Zeph. Her role was to hold our feet to the fire about adult issues. She was the one who kept ringing the bell about that and is very committed to that issue. Anything else on the Family/Personal roster? Okay, what about the Research list here?

Mr. Grossman: I think the best person on that list (although it is a great list) but my number one pick would be Brenda Myles.

Ms. Blackwell: And I can't think of a better person than Charlie Lakin from the University of Minnesota. Charlie wasn't able

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to join us last year but he has knowledge of the service system across the United States and he's just such a nice guy. We haven't had the privilege of working with him yet but I think he could add a lot to our strategic plan.

Dr. Trevathan: Since I mentioned George Jesien before I'll mention him again. I think in this question he would be appropriate for the research category and I think from a services point of view on research on how to improve services he's in a really good position to understand those questions. He understands service issues and research in those areas really all over the country so I think George would be excellent.

Dr. Insel: David Mandell - I think you know him. He was on the previous work group and David's real interests are systems of care and doing research on service delivery access. He's based in Pennsylvania. He is probably

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the number one researcher for autism. Any points about the other people on the list? We will add Henry Claypool to the IACC liaison list.

Dr. Trevathan: I don't think I fully recognized as I went through the list but I keep seeing my name on here and I'm very flattered but I just wonder if I am needed on this IACC liaison for Panel 5. We have all of the areas of expertise covered and I'd be happy to take my name off this one as a candidate unless you feel that would be inappropriate. I want to do a good job but I don't think it would be good for me personally to be on more than two panels.

Dr. Insel: We were hoping that no one would be on more than one if we could work it out right so the committee will be advised to not nominate Ed. Other issues with rosters as you're looking at them?? Della - do you want to take us through the next steps?

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Dr. Hann: Based on today's discussion, we will prepare essentially we will refer to it as a ballot. It will be by panel and by the area of expertise - clinical, researcher, and family/personal. It will contain a list of names that you have before you as well as those that you mentioned today and as well as the one deletion that we just went through or the liaison role. Hopefully I'll be able to get that out to you possibly this evening or early tomorrow morning. We would like to move on this relatively quickly because with the workshop coming up at the end of September we need to move forward. You'll be asked when you receive this to choose three people per area - so within a panel, 3 clinicians, 3 researchers, and 3 family members. And we'll also be asking you to nominate 3 IACC liaisons. We went back and forth as to whether it would be necessary to rank order and we decided that no, just put an x next to

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the person's name. We will then take everyone's tallies and do a spreadsheet and indicate who got the most votes for a given area. If there's an area for which we have a tie, we will probably come back to you with that information. If we have areas where a given individual has been nominated for more than one panel we may bring that back to you as well. I think given the amount of work that we're asking these people to do, I want you all to be certain you want to nominate them for two panels as opposed to just one. I will try to get that ballot out to you tonight. If you have any questions, always feel free to let me know. And I'm going to ask for a quick turnaround. Essentially try to get this back to me by close of business this Friday so that we can proceed with collecting all of the information and if we need to get back to you to be able to do so early next week. We'll certainly get back to

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you too with the final roster as well.

Mr. Grossman: Is the ballot as well for the IACC liaison?

Dr. Hann: That is correct.

Mr. Grossman: And with that you are looking at one public member and one government member from the full IACC?

Dr. Insel: That's right.

Dr. Hann: I think it would be good for each panel that somebody from this planning committee be involved just because you have more knowledge for what we're looking for.

Dr. Insel: Any further questions about this? We have one other item that we would like your feedback and that is with the agenda for the September 30<sup>th</sup> meeting. Della - do you want to take them through this? It is pretty straight forward as to how we want to allot the time. Give us your best ideas as to how you want this to run.

Dr. Hann: In the email that I sent out

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to you about a week ago there were two attachments for possible agendas for the scientific workshop. They are very, very similar and based on the discussions that we had - one of them essentially is shorter in terms of time than another so for example - looking at the one I will call the short one.

So for Day 1 obviously we would begin the day with welcoming and introductions of course.

The first one is Panel One - Should I Be Concerned and allotting a half hour for presentation of our experts followed by another half hour of discussion with full group of panelists across all panels and then another half hour that would be open for public Q&A kind of thing. That's the shorter version. The longer version flows identical to that; it's just that we allow more time for discussion. There's still a half hour for the joint presentation, there's now 45 minutes for the panelists to have a discussion, and

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another 45 minutes for public discussion.

Ms. Redwood: Are you wanting us to decide today on which agenda?

Dr. Hann: I think it would be helpful because I think we need to let the people know what the expectations are.

Ms. Redwood: I'm one to say we need more time. I think for some reason if we go short we can always move forward but I think we should take the side of allotting as much time as possible so that we have time for discussion.

Dr. Insel: What's the sense of others in the group? (All agree)

Dr. Hann: Do we have anyone that objects to going longer? (negative)

Dr. Insel: Very good. Any other issues that anyone from the planning group wants to bring up? Excellent. Well, thanks everybody for joining us and as Della mentioned to you we will be back to you very quickly with the

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ballots and we would appreciate a rapid turnaround so that we can move forward with the final roster. And we will be doing this again in about a year. This is an annual event. Thanks everyone and have a good rest of the week. Bye-bye!

(The meeting was then adjourned.)

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